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ABSTRACT

The booklet describes an approach to individualizing parent involvement in special education programs. A family needs checklist addresses parents' knowledge (of community resources, educational programing, support services, and general information about normal developmental levels and tests and measurement); support; skills in working with children; and willingness to be involved in parent programs. An activity list parallels the needs checklist and lists possible activities for each need. A final section examines types of activities, including information packets, group speakers, individual parent-staff conferences, lending library services, and workshops and conferences. (CL)

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INDIVIDUALIZING PARENT INVOLVEMENT

INTRODUCTION

Parent involvement, as a concept, is generally accepted as a primary component of any early childhood/handicapped program. The concept, however, means many different things to various individuals: parents as teachers, parent support groups, parent advocacy, parent counseling, etc. Although various fads in parent involvement might influence the popularity of any of these components, in general, parent involvement should be an inclusive, rather than exclusive, concept.

For a long time, parent involvement activities have been viewed as group activities. In a sense, parent involvement meant parent groups. Yet a large proportion of parent programs have reported that regardless of the activity only about 40 percent of the parents attended any given meeting. An analysis of those parents who attend such meetings revealed that approximately 20 percent attend all meetings! These are the "old faithful"--they will attend any meeting concerning their child. The other 20 percent of the parents attend the meetings depending upon the scheduled activity. Thus, in discussions of parent involvement, there tend to be three groups of parents: (1) those who attend all activities, (2) those who attend some activities, and (3) those who never attend.

While educators have taken many positive steps toward improved parent involvement (e.g., getting parents' suggestions for meeting topics, altering meeting times, providing child care services, serving refreshments), these traditionally have not resulted in increased parent participation.

The ideas in this paper come from four sources. The first is an article* by Bricker and Casuso (1979) which describes an individualized parent program. Basically, this plan calls for assessing parent (family) needs, determining priority objectives for parents, and developing an individual parent plan (IPP) which includes activities directly related to the stated objectives. These activities may or may not be group activities. Following the activity, an evaluation determines if the objective has been achieved. If so, a new objective is selected. If not, an alternative activity is selected and the cycle repeats. In essence, this model is identical to an individualized approach to intervening with children.

The second source of information was Project KIDS Outreach in Dallas, Texas, directed by Ruth Turner. This project, working independently of Bricker and Casuso, has developed an individualized parent involvement program based on a 19-point assessment device with a list of possible activities that can be used when a need is indicated. Using this procedure, the Project KIDS staff developed individual parent plans for approximately 90 percent of their parents.

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* Bricker, D., & Casuso, V. Family involvement: A critical component of early intervention. Exceptional Children, 1979, 46, 108-117.

The third source was a WESTAR-sponsored workshop which brought together 15 parent involvement specialists from Nebraska, Idaho, and California, four mothers of young (pre-6) handicapped children, and several WESTAR staff. This group, over a two-day period in May 1978, developed tentative assessment procedures and remedial activities based on the models suggested by Bricker and Casuso, and Turner.

The fourth activity contributing to this paper was a course in the College of Education at the University of Washington, "Interactions for Families of Handicapped Children." Students in the class refined and field-tested the procedures developed by the workshop group.

There are 5 basic components to this total parent packet: (1) Hints for Determining Parent Needs, (2) Family Checklist (parent assessment device), (3) Activities List, relating to the Checklist, (4) Comments on Activity List, including evaluation ideas, and (5) a form for recording parent activities.

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PART 1
HINTS FOR DETERMINING PARENT NEEDS

The entire approach to parent involvement presented in this paper is based on the assumptions of mutual trust and respect between the professional and parent. Second, the professional must be totally convinced of the importance of parental involvement and the integrity of each parent. Given these two tenets, each program must develop its own parent involvement program. The following materials are presented to guide this development. NONE OF THESE MATERIALS SHOULD BE USED AS THEY ARE--they should be modified and adapted to fit the special needs of each program. Remember, only promise to do what you can actually do. In other words, "underpromise" rather than overpromise.

The initial contacts with parents should be geared to establishing rapport, gaining information, giving information, and in general, setting the tone for all future meetings. At some point, you will want to begin to establish a formal parent program with each parent. The following steps provide a general outline for such a procedure.

1. Contact parents and schedule a mutually agreeable time and place for the meeting. It is critical that both parents are included in this meeting. If possible, provide child care for the family.

2. Explain that the purpose of the meeting is to develop a program for the parents, one which will be designed to help them with their child.

3. At the beginning of the meeting, describe the steps of the parent involvement program to the parents: (a) systematic look at typical parent needs, (b) mutual agreement on topics of concern, (c) arrangement of activities to meet their needs, (d) evaluation of the activities to see if they worked, and (e) repetition of the process as needed.

4. Using a version of the attached Family Needs Checklist, determine parents' perceptions of needs. Be careful of your terminology. Try not to use jargon. Be positive and supportive.

5. After the needs assessment is completed, mutually choose two or three topics that will become the major focus of the parent program.

6. Review the list of possible activities for each of the identified topics.

7. Together with the parents, choose one activity for each topical area.

8. Fill out Family Plan form with parents.

9. Arrange to begin at least one activity.

10. Evaluate the effectiveness of the activity; e.g., Were the parents pleased? Do they still feel a need for more input? etc.

11. Analyze the data; e.g., Are the parents ready for a new objective? Do they need more time on the present objective? Was the activity successful?

12. Recycle. If the parent has achieved the objective, move on to another mutually agreed-upon topic. If they have not met the objective but are making progress with the current activities, continue the activities. If they have not met the objective and the activity is completed or is considered not appropriate, select a new activity.

PART 2
FAMILY NEEDS CHECKLIST

SECTION 1: KNOWLEDGE

	YES	NO	COMMENTS
Do you have questions about:			
I. Community Resources			
A. Diagnostic, evaluation and treatment sources			
1. Physician			
2. Physical therapist			
3. Occupational therapist			
4. Speech/hearing therapist			
5. Counseling			
6. Vision testing			
7. Orthopedics			
8. Public health care			
9. Genetic counseling			
10. Dental health			
11. Advocacy groups			
B. Educational programming			
1. Attending a parent group meeting			
2. First aid procedures			
3. Sex education			
4. Laws relating to special education			
5. School programs available for your child			

	YES	NO	COMMENTS
6. Reports from your child's teachers, therapists, etc.			
C. Support services			
1. Respite care			
2. Transportation			
3. Supplemental Security Income			
4. Recreation			
5. Aid to Dependent Children			
6. Day care			
7. Babysitting			
8. Food stamps			
9. Housing			
10. Legal aid			
11. Health insurance			
12. Financial information			
13. Support groups (e.g., Association for Retarded Citizens, United Cerebral Palsy, etc.)			
14. Schools--private, public, Head Start, residential services			
15. Availability of religious instruction for your child			
16. Programs funded by the state, federal agencies, and local foundations			
II. General Information			
A. Handicapping conditions/ labels			

	YES	NO	COMMENTS
B. Normal developmental levels			
1. Motor/physical development			
2. Language/communication skills			
3. Cognitive/learning abilities			
4. Self-help skills			
5. Social skills			
C. Tests and measurement			
1. Reasons for testing			
2. Results of tests			
3. How tests affect my child			

SECTION 2. SUPPORT

Would you like to have the opportunity to discuss:

A. Concerns about how your child relates to the family			
B. Concerns about your child's future			
C. Concerns about the public's reaction to your child's handicap			
D. Concerns about how your life will or has change(d)			

SECTION 3. SKILLS IN WORKING WITH A CHILD

	YES	NO	COMMENTS
Would you like to have the opportunity to learn how to work with your child in:			
A. Self-help			
1. Eating			
2. Dressing			
3. Toileting			
4. Hygiene			
B. Motor			
1. Gross (large)			
2. Fine (small)			
C. Language			
1. Expressive (verbal, nonverbal)			
2. Receptive (understanding)			
D. Cognitive (learning)			
E. Social			
1. Play independently			
2. Play with others/peers			
3. Play with adults			
F. Behavior problems/management			
G. Nutrition			

SECTION 4. PARENT PARTICIPATION

Would you be willing to:			
A. Provide transportation			

	YES	NO	COMMENTS
B. Provide respite care			
C. Provide help in classroom			
D. Speak to groups			
E. Work with local chapters of national organizations			
F. Provide home for meetings			
G. Help others with advocacy			
H. Influence legislative bodies			
1. Telephone			
2. Write letters			
3. Attend hearings			

COMMENTS:

PART 3
ACTIVITY LIST

The Activity List parallels the Family Needs Checklist. For each item on the first three sections of the checklist, a corresponding item on this list will provide appropriate activities. Obviously, each program will have to create its own assessment and corresponding activity list. Each item on the assessment must have at least one activity that could ameliorate the stated need. Each program will have to decide which activities it can sponsor.

SECTION 1. KNOWLEDGE

I. Community Resources

A. Diagnosic, evaluation, and treatment sources

1. Physician	- Current resource list of physicians - M.D. to speak to parent group - Tour of medical facility
2. Physical therapist	- Resource list of services available and fees - Resource list of special centers - Therapist to speak to group - Written overview of services
3. Occupational therapist	- Resource list of services available and fees - Resource list of special centers - Therapist to speak to group - Written overview of services
4. Speech/hearing therapist	- Resource list of services available and fees - Resource list of special centers - Therapist to speak to group - Written overview of services
5. Counseling	- Resource list of mental health agencies - List of parents (to talk with new parents) that have children with same handicapping condition - Resource list of private services available and fees - List of available films, slides, etc. - List of books
6. Vision testing	- Resource list of free vision testing clinics - Nurse/M.D. speaker for parent groups - List of facilities providing services and fees

7. Orthopedics	- Resource list of special centers - M.D. speaker for parent groups - List of facilities providing services and fees
8. Public health care	- Current list of public health facilities and services they offer - Follow-up with contact person at agency
9. Genetic counseling	- Resource list of available services and fees - Specialist to talk to parent group - Panel discussion with parents and professionals - List of sources of funds for genetic counseling
10. Dental health	- Resource list of available services and fees (i.e., dentists willing to work with handicapped) - Specialist to speak with parent group - Resource files of parents that have received adequate services
11. Advocacy groups	- Resource list of active groups and contact persons - Information center - File of newsletters (Parent Library) - Member of appropriate group to speak with parent group
B. Educational programming	
1. Attending a parent group meeting	- A list of groups in community, with phone number of contact parent - Card catalogue with names and phone numbers of parents interested in parent-to-parent programs including: age of child, handicapping condition, marital status. - Teacher to speak with parent group about educational programming
2. First aid procedures	- List of available classes in community - Volunteer instructor to talk to parent group - Books and pamphlets available (Parent Library) - Audio-visual demonstrations

3. Sex education	- Parent library - Professional to speak to parent group - Card file of contact persons with older children with similar handicapping conditions - Panel discussion with parents and professionals - Speaker on legal issues dealing with sexuality of handicapped individuals - Audio-visual information on sex education
4. Laws relating to special education	- List of legal and paralegal agencies dealing with rights of handicapped individuals - Available printed material (Parent Library) - Professional speaker to discuss and interpret laws - Resource list of advocacy/legislative workers - Class on legal rights
5. Educational programming available (school programs)	- Teachers to discuss programs available to parent groups - Resource list of programs available - Parent-to-parent sharing of information on programs - Tour/observation of programs available - Parents spend time in different programs
6. Feedback from educational program	- Teachers discuss feedback with parents - Handbook on how feedback problems/ procedures are used. - Role-play types of feedback procedures. - Teachers and parents form working task force on feedback procedures - Individual conferences between teachers and parents
C. Support services	
1. Respite care	- Resource list of agencies providing services and fees - Printed material available for respite care facilities - Speaker from respite care agency at parent meetings - Parent-to-parent cooperative respite care programs

	- List of families that are willing to provide respite care - Visitation to respite care facilities - Training for parents interested in giving respite care - Information on current foster grandparents program
2. Transportation	- Resource card file on parents willing to provide cooperative transportation (car pool) - Resource list of all accessible public transportation - Resource list of any agency providing transportation (FISH, etc.) - Parent discussion on problems of transportation for the handicapped - Parent handbook describing available transportation and the legalities thereof.
3. Supplemental Security Income	- Current printed material - Resource list of agencies dealing with SSI and names of contact persons - Parent-to-parent group meeting to discuss eligibility and problems encountered with SSI
4. Recreation	- Current resource list of available pools, parks, etc. - Current resource list of city and county programs - Resource list of contact persons at city and county park and recreation programs - Speaker to talk about accessible programs - List of parents in specific programs to provide feedback - List of recreation instructors working with the handicapped (e.g., swimming, horseback riding, piano, etc.)
5. Aid to Dependent Children	- Printed material available (Parent Library) - Legal specialist to discuss eligibility - Parent advocate
6-7. Day care, babysitting	- See C1, Respite care

8. Food stamps	- Printed material available (Parent Library) - Panel discussion on eligibility - Speaker to discuss program - Resource list of distribution centers, agencies that would have information, and contact persons within agency
9. Housing	- List of group homes and residential programs - Information regarding legal aspects of housing, fees and available funding - Parent-to-parent contact with parents who have children in housing outside of family - Information on alternatives to residential care - Visits to alternative housing situations
10. Legal aid	- Information on legal and paralegal persons involved with rights of the handicapped - List of legal and paralegal services and fees - Legal personnel to speak to parent groups - Printed material available on legal rights of handicapped individuals
11. Health insurance	- Representative from insurance companies speak to parent groups - Information available on health insurance, life insurance and fees from different agencies - Resource file on private insurance plans and names of contact persons within agencies
12. Financial information	- Information on funding available through state agencies - Legal or paralegal speaker to discuss legal issues on financial support - List of advocacy groups, e.g., troubleshooters and contact persons within groups
13. Support groups (e.g., ARC, UCP)	- Resource list of organized support groups and contact persons - Speaker from support group to talk with parents group - Visits to support group meetings - Printed material on organized support groups

14. Schools--private, public, Head Start, residential services	- Printed material on programs - Observation of various school programs - School personnel to speak with parent group - List of school placements and contact persons within program - Resource list of Head Start programs and residential services available
15. Religious instruction	- Resource list of available religious programs - Personnel from religious program to speak with parent group
16. Programs through state, local and federal agencies	- Resource list of programs offered through state, local and federal agencies - Panel discussion with representatives from various agencies - Program visitations - Reference list of contact persons within agencies
II. General Information	
A. Handicapping conditions/ labels	- Parent handbook of terminology - Speaker to discuss specific handicapping conditions and the implications - Resource file (and phone numbers) of parents of children with specific handicapping conditions - Printed materials - Audio-visual materials - Ongoing parent classes - Resource list of contact agencies in community that could provide information
B. Normal development	- Printed material - Audio-visual aids on normal development - Therapist to talk with parent group on gross and fine motor, speech/language development, etc. - Referral to specific community classes on development - Workshop for parents - Physician to explain well-baby examination - Calendar of developmental milestones - Share preschool or other developmental assessments - Involve parents in assessment process

C. Tests and measurements

1-2. Reasons for testing and results	- Professional to speak with parent group - Printed material on testing - Parent conference with professionals administering tests - Panel discussion on measurement - Parents involved in testing procedure
3. How will tests affect my child?	- Parent-to-parent contact with parents who have been through testing procedures - Panel discussion on implications of testing and measurement - Printed material available on meaning of testing - Information available on legal aspects of testing and measurement

SECTION 2. SUPPORT

A. Concerns about how the child relates to the family	- Resource list of family-child service agencies - Parent-to-parent contact - Home observations of child and family with active ongoing feedback system - Panel discussion on handicapped children and their families - Printed material (Parent Library)
B. Concerns about your child's future	- Resource list of support groups - Resource list of parents with older handicapped children - Panel discussion on legal rights of handicapped adults - Agencies dealing with handicapped adults - Material available on programs and living situations for handicapped adults
C. Concerns about public reaction	- Parent-to-parent contact groups - Resource list of support/advocacy groups
D. Concerns about how your life will or has change(d)	- Parent contact with parents of handicapped adolescents and adults - Parent group meeting - Resource list of support groups and names of contact persons within group

SECTION 3. SKILLS IN WORKING WITH A CHILD

A. Self-help

1-4. Eating, dressing, toileting, hygiene

- Individualized programs developed by PT, OT, teacher
- Parent involvement in assessment and ongoing program
- Parent training for specific skill areas
- Parent visit to school program
- Calendar of normal self-help developmental milestones
- Demonstrations by professionals of specific programs with measurable goals
- Parent involvement in writing and rewriting goals
- Videotape feedback of child's program
- Resource list of home aides to assist with home programming
- Printed material (Parent Library)
- List of available adaptive equipment and costs
- Home visits by professional to assist in carry-over at home

B. Motor

1-2. Gross, fine

- Individual parent training by therapist following parent participation in assessment
- Individualized programs developed by PT, OT, teacher
- Parent involvement in assessment and ongoing programs
- Parent training for specific skill areas
- Parent visit to school program
- Calendar of normal self-help developmental milestones
- Demonstrations by professionals of specific programs with measurable goals
- Parent involvement in writing and rewriting goals
- Videotape feedback of child's program
- Resource list of home aides to assist with home programming
- Printed material (Parent Library)
- List of available adaptive equipment and costs
- Home visits by professional to assist in carry-over at home

C. Language

1-2. Expressive, receptive

- Communication Disorders Specialist (CDS) to discuss alternative language approaches
- Individualized program developed by PT, OT, teacher
- Parent involvement in assessment and ongoing program
- Parent training for specific skill areas
- Parent visit to school program
- Calendar of normal self-help developmental milestones
- Demonstrations by professionals of specific programs with measurable goals
- Parent involvement in writing and rewriting goals
- Videotape feedback of child's program
- Resource list of home aides to assist with home programming
- Printed material (Parent Library)
- List of available adaptive equipment and costs
- Home visits by professional to assist in carry-over at home

D. Cognitive (learning)

- Individualized program developed by PT, OT, teacher
- Parent involvement in assessment and ongoing program
- Parent training for specific skill areas
- Parent visit to school program
- Calendar of normal self-help developmental milestones
- Demonstrations by professionals of specific programs with measurable goals
- Parent involvement in writing and rewriting goals
- Videotape feedback of child's program
- Resource list of home aides to assist with home programming
- Printed material (Parent Library)
- List of available adaptive equipment and costs
- Home visits by professional to assist in carry-over at home

E. Social

1-3. Play independently, with others/peers, adults

- Individualized program developed by PT, OT, teacher
- Parent involvement in assessment and ongoing program
- Parent training for specific skill areas
- Parent visit to school program
- Calendar of normal self-help developmental milestones
- Demonstrations by professionals of specific programs with measurable goals
- Parent involvement in writing and rewriting goals
- Videotape feedback of child's program
- Resource list of home aides to assist with home programming
- Printed material available (Parent Library)
- List of available adaptive equipment and costs
- Home visits by professional to assist in carry-over at home

F. Behavior problems

- Individualized program developed by PT, OT, teacher
- Parent involvement in assessment and ongoing program
- Parent training for specific skill areas
- Parent visit to school program
- Calendar of normal self-help developmental milestones
- Demonstrations by professionals of specific programs with measurable goals
- Parent involvement in writing and rewriting goals
- Videotape feedback of child's program
- Resource list of home aides to assist with home programming
- Printed material (Parent Library)
- List of available adaptive equipment and costs
- Home visits by professional to assist in carry-over at home

Management strategies--
physical and emotional

1. Handicapped child
   - Parent handbook of terminology
   - Printed material (Parent Library)
   - Audio-visual aids for home management
   - Parent-to-parent contact to discuss problems encountered within the home management system

2. Siblings
   - Parent-to-parent contact with parents that have siblings of handicapped child

G. Nutrition

1. Information about nutrition
   - Professional to speak with parent group
   - Nutritional information packets
   - List of community service agencies with information on nutrition
   - Panel discussion on nutritional needs of children
   - List of adaptive feeding equipment

PART 4
COMMENTS ON ACTIVITY LIST

Each activity should be easily evaluated in terms of parent satisfaction and eventual indication that the stated need has been satisfied. Also, each of the items could be handled in a group situation or individually. Remember, to truly individualize, parents must be able to assist in the selection of the activity and its location.

The following section lists some of the types of activities, special considerations for each activity, and a brief statement as to evaluation procedures. The purpose of evaluation is to improve the activities to better meet the stated parent objectives. Thus evaluation is decision making--altering activities that do not help the parents meet their objectives, adding activities, or allowing activities to continue because the parents did meet their stated objectives. This requires careful planning, developing means to collect information, collecting the information, analysis of the information, and use of the information in decision making.

INFORMATION PACKETS

1. Should be subject-specific (e.g., counseling agencies, dentists, parent support groups, etc.).
2. Should include name of contact person. This person should be informed that their name is being placed on the list.
3. Should include prices of materials and costs of services whenever possible.
4. Must be specific to geographical area.
5. Must be updated. (Note: the updating process can often be a meaningful parent activity.)

The evaluation of these information packets includes: (1) frequency of use, (2) reported satisfaction, and (3) reports that the information was accurate.

GROUP SPEAKERS

1. Should be obtained in reference to specific, stated, parent needs (e.g., legal rights, insurance, nutrition, etc.).
2. Try to use only speakers you personally have heard and know are good.
3. Try to use parents as speakers whenever possible.
4. Try to have speakers agree to interact with parents individually and free-of-charge after they have made their presentation.

The evaluation of speakers is often difficult. One alternative is to have parents fill out a formal evaluation form. Another is to ask the speakers to evaluate their talk and report back to you.

INDIVIDUAL PARENT-STAFF CONFERENCES

1. Have specific agenda for conference, with objectives.
2. Mutually agree on meeting time.

3. Write down outcome.
4. Use third-party mediation if problems arise.
5. Be sure to distinguish between information (knowledge sharing) meeting and skill-building meeting.

These interactions need to be evaluated as to accomplishment of the meeting's objectives (Item 1).

LENDING LIBRARY (BOOKS/TOYS/ETC.)

1. Only include items you or your staff are familiar with.
2. Keep up-to-date lists of what is available.

The evaluation of library materials may include both usage data as well as satisfaction reports.

WORKSHOPS AND CONFERENCES

1. Make sure topics were generated by parents.
2. Make sure time of activity is agreeable to those parents who indicated need.
3. Involve parents in planning--maybe even sponsor a parent conference for parents, by parents.
4. Specify if each session is for information exchange or skill building.
5. Carefully evaluate each session.
6. Use proven leaders.

The evaluation of these activities is most often done by the presenters. The evaluations should include measures of participant satisfaction and skill acquisition.

PART 5
FAMILY PLAN FORM

NAME _____

NEED	ACTIVITIES	DATE	RESULTS